



# **Doctors' Attitudes to Consent and Shared Decision making**

**Full Research Report for the GMC**

**Final version**

**June 2017**

**All interpretation and opinion in this report is that of the authors alone and does not necessarily reflect those of the General Medical Council.**

**The authors would like to thank all participating doctors for their frank and honest contributions to this research.**

## Contents

1. Executive summary.....	4
1.1 Objectives and methodology .....	4
1.2 Key findings .....	4
2. Background, objectives and methodology.....	7
2.1 Background.....	7
2.2 Research objectives .....	7
2.3 Methodology .....	7
2.4 Notes on reading the report .....	10
3. Overall awareness and attitudes .....	11
3.1 Awareness of the key principles of consent and the GMC guidance .....	11
3.2 Attitudes towards consent guidance .....	13
3.3 Current practice.....	15
3.4 Awareness of changing practice.....	16
3.5 Experience of relevant training .....	17
4. Key challenges associated with meeting the guidance.....	19
4.1 Systemic/organisational level.....	19
4.2 Individual patient level .....	22
4.3 Individual doctor level.....	26
4.4 Grouping the key challenges: ability, willingness and opportunity .....	29
5. Examples of good practice in consent and shared decision making .....	30
6. Sources of support and guidance.....	32
6.1 Response to GMC existing guidance.....	32
6.2 Response to alternative sources of support / guidance.....	32
7. Detailed review of the GMC guidance.....	34
7.1 Initial reactions.....	34
7.2 Structure and layout .....	35
7.3 Missing elements .....	35
7.4 Review of specific sections .....	35
8. Looking ahead: addressing the challenges.....	39
8.1 Doctors' suggested improvements .....	39
8.2 Linking solutions to challenges .....	43
Appendix 1 - Participant profiles .....	45
Appendix 2 - Summary of specific comments on the guidance .....	47
Appendix 3 - Research instruments .....	49

## 1. Executive summary

### 1.1 Objectives and methodology

This research project forms part of an extensive consultation and engagement exercise the GMC is undertaking to inform the revision of its guidance for doctors on consent and shared decision making<sup>1</sup>, which was last published in 2008. The overarching aim of the research is to explore doctors' awareness and understanding of the principles of consent and shared decision making and the challenges they face when implementing these in their daily practice environments. The GMC wants to understand the weight that doctors place on the importance of following these principles in practice, in and of itself, but also when there is a conflict between principles or when facing time or other pressures. A secondary objective is to provide detailed feedback on the guidance.

A series of extended discussion groups and in depth interviews was conducted in order to provide an opportunity for deliberation and discussion. Nine discussion groups and one individual in-depth interview were conducted with doctors across the UK. At the end of each discussion group or interview, all participants were asked if they were willing to read through the consent guidance in more detail and share their thoughts via an online bulletin board. This resulted in 28 of the 47 doctors who took part in the first stage actively taking part in the bulletin board, giving their responses to specific questions about the guidance.

### 1.2 Key findings

Doctors were familiar with the broad principles of consent and shared decision making and demonstrated a willingness to adhere to them, to varying degrees. However, they often placed the emphasis on presumed capacity and the need to have a dialogue with the patient and inform them of the risks, common and rare, of a procedure or treatment. The need to individualise the conversation was less top of mind; and across the groups awareness of the Montgomery ruling<sup>2</sup> was low. Further discussions revealed that many doctors were concerned that they did not have the time to understand the needs and wants of individual patients and, therefore, to truly personalise the consent process; they questioned the implications of the judgement and the GMC guidance given these time constraints.

#### ***Identified challenges***

In addition to feeling under time pressure, doctors raised a number of specific challenges associated with being able to meet the guidance on consent and shared decision making. These included:

- Difficulties with assessing the capacity of a patient – particularly when the patient has fluctuating capacity, and/or when the patient is making a seemingly irrational decision.

---

<sup>1</sup> [http://www.gmc-uk.org/static/documents/content/Consent\\_-\\_English\\_1015.pdf](http://www.gmc-uk.org/static/documents/content/Consent_-_English_1015.pdf)

<sup>2</sup> <https://www.supremecourt.uk/cases/uksc-2013-0136.html>

- Being able to understand what is important to individual patients; the range of patient attitudes and expectations.
- Being able to provide complex information to patients in a way that patients can understand.
- Lack of up to date knowledge of some procedures and treatments – and their risks and benefits - amongst some doctors.
- Dealing with family who may have different views to the patient and different expectations of the doctor.
- Both patients and doctors adapting to the changing patient-doctor relationship.

### ***Sources of guidance and support***

Few doctors had detailed knowledge of, or saw a particular need to refer to the GMC's guidance on consent and shared decision making. Those most familiar with GMC guidance often had additional roles aside from their main job. Instead doctors rely heavily on other organisations and colleagues for support and guidance. When doctors had sought advice and support from an external organisation they referred to:

- Royal Colleges.
- Medical Defence Unions.
- The BMA.
- Third sector organisations for patient information.
- Local government sources.

Doctors who took a more detailed look at the guidance on consent and shared decision making were broadly positive towards it, although some suggested there was opportunity to make it more 'reader friendly'. Although not disagreeing with the content, they all raised the point that the guidance sets out a 'gold standard' that is not always achievable in practice due to the time constraints they work under.

The main area where they called for more information or guidance was in the section on Capacity Issues, including:

- Establishing capacity of patients who do not speak English.
- Guidance on when to seek a second opinion.
- Greater focus on the need to constantly re-evaluate capacity.
- How to deal with potential disagreements within families.
- Links to organisations that may be able to offer help with capacity issues.

### ***Suggested best practice and potential solutions***

A number of doctors were able to give examples of best practice that they had adopted as individuals or as part of a wider team. Some of these were reflective of the GMC guidance on consent and shared decision making. For example:

- Assessing capacity at a time of day when the patient is more likely to have capacity to consent.
- Giving the patient the opportunity to reflect and return for another appointment.

Doctors called for a range of support to further improve their practice on consent and shared decision making, not all of which is within the remit of the GMC

- Production of standardised resources for doctors which outline the benefits and risks of common treatments or procedures.
  - Although some doctors argued against this as standardised information was regarded as being counter to the need to tailor information to the individual.
- Promoting methods and producing resources for explaining risks (in ways that patients understand.)
- More evidence being made available to doctors about the risks of procedures/treatments.
- More evidence about the overall benefits of consent and shared decision making.
- Support for smarter ways of working i.e. using new technologies in practice.
- Patient/public education campaigns as a way of helping patients understand the principles of shared decision making and the role their role within it. Increased training opportunities/resources.
- More time and resources available within the NHS to ensure that doctors are able to implement good practice

## **2. Background, objectives and methodology**

### **2.1 Background**

Consent is one of the core ethical foundations on which the doctor-patient relationship is based, and it raises some complex ethical and legal issues. Consent guidance was last published in 2008 and, since then, a number of developments mean GMC guidance may no longer adequately reflect the legal position and the wider policy environment and it may not be meeting doctors' needs.

The GMC believes that, even though doctors may not be familiar with the consent guidance in detail, they do understand what is expected of them. However, the GMC knows from its own research and from working with doctors, that doctors may face challenges in implementing these principles, for example time pressures or patients whose first language is not English. This can lead to poor practice and, in some cases, complaints. It is, therefore, important for the GMC to understand these challenges and what role they might be able to play in addressing them as a regulator.

This research project forms part of an extensive consultation and engagement exercise the GMC is undertaking to inform the revision of its guidance for doctors on consent.

### **2.2 Research objectives**

The overarching aim of the research is to explore doctors' awareness and understanding of the principles of consent and shared decision making across the four countries and the challenges they face when implementing these in their daily practice environments. The GMC would like to understand the weight that doctors (working in different specialisms and at different stages of their career) place on the importance of following these principles in practice, in and of itself, but also when there is a conflict between principles or when facing time or other pressures.

Secondary objectives are to explore the following:

- Whether the guidance is covering the right topics and in the right level of detail.
- Whether doctors think there are any areas within the guidance that need to be updated, added to or corrected.
- Whether the guidance is structured in a way that is user-friendly.

### **2.3 Methodology**

#### ***Overall approach***

The overall approach was a combination of face to face discussions and an online bulletin board. A series of extended discussion groups and depth interviews was conducted to provide an opportunity for deliberation and discussion on what doctors think about the principles of consent and shared decision making and the challenges they face. Group numbers were limited to ensure that each participant would have the

time and space to articulate their views and so that the moderators had scope to explore individual perspectives in depth.

Nine discussion groups and one individual in-depth interview were conducted and in total 47 doctors participated in the first phase of the research. The sample was designed to ensure that the research elicited a range of views:

- Across England, Wales, Scotland and Northern Ireland.
- Across doctors working in a range of specialisms.
- Taking into account different career stages (doctors that qualified less than 10 years ago versus doctors who qualified more than 10 years ago).
- Including a number of doctors who had trained outside of the UK.

The precise mix of groups and interviews is shown in Table 1.

**Table 1- Research groups and interviews**

Group no.	Number of participants	Specialism	Experience	Location	Date of group
1	6	Mental Health	Less than 10 years of experience i.e. FY1, FY2, SpR. Recruit a spread	Leeds	6 <sup>th</sup> February
2	5	Mental Health	More than 10 years of experience i.e. consultant	Edinburgh	13 <sup>th</sup> February
3	3, plus one depth interview conducted in Glasgow	GP	Less than 10 years of experience Recruit a spread	Edinburgh	14 <sup>th</sup> February
4	6	GP	More than 10 years of experience	Stockport (drawing on surrounding rural locations)	2 <sup>nd</sup> February
5	6	Surgery	Less than 10 years of experience i.e. FY1, FY2, SpR. Recruit a spread	London	1 <sup>st</sup> February
6	7	Surgery	More than 10 years of experience i.e. consultant	Birmingham	8 <sup>th</sup> February
7	4	Mixed secondary care	Less than 10 years of experience i.e. FY1, FY2, SpR. Recruit a spread	Belfast	6 <sup>th</sup> February
8	6	Mixed secondary care	More than 10 years of experience i.e. consultant.	Cardiff	1 <sup>st</sup> February
9	3	Mixed secondary care	All trained outside of UK and/or English as a second language	London	7 <sup>th</sup> February



At the end of each discussion group or interview, all participants were asked if they were willing to read through the GMC's consent guidance in more detail and share their thoughts via an online bulletin board. This resulted in 28 of the 47 doctors who took part in the group discussions actively taking part in the bulletin board, reading the guidance and leaving comments to specific questions about the guidance. A breakdown of bulletin board participants can be seen in Appendix 1.

### ***Sampling and recruitment process***

Participants for the initial group discussions were recruited by Acumen Fieldwork to an agreed specification. Acumen specialises in medical market research recruitment and has extensive expertise in recruiting health professionals. The agreed recruitment specification covered a number of variables, including gender, ethnicity, length of time since qualification, specialty and country of qualification. A profile of participants is provided in Appendix 1.

Participants were given an incentive in cash, or an equivalent charitable donation, as a thank you for their attendance and as a goodwill gesture to acknowledge the time taken to participate. Those who contributed to the online bulletin board received an additional incentive.

### ***Fieldwork process***

#### *Group discussions*

All groups and interviews were conducted during a period from the 1<sup>st</sup> February until the 14<sup>th</sup> February 2017.

Discussions followed a semi-structured guide in order to allow participants to elaborate on and discuss their views and perceptions freely. The discussions were facilitated by Community Research, an independent research organisation, commissioned by the GMC. The groups were audio recorded and transcribed. The discussion guide and stimulus materials used are provided in Appendix 3. Hypothetical scenarios were used during some group sessions to help stimulate discussion.

#### *Online bulletin board*

The online bulletin board was 'live' from 8<sup>th</sup> March until 22<sup>nd</sup> March. During this time the registered participants were asked by Community Research to leave comments relating to specific sections of the guidance and any further support they required in order to meet the guidance. Questions posted are shown in Appendix 3.

By its nature, qualitative research generates a large volume of data. In this case, all of the discussions were audio-recorded (with the participants' knowledge and permission) and then transcribed in full. The comments left on the online bulletin board were all exported to a Microsoft Word document. Several researchers then undertook analysis independently and simultaneously, and compared results to ensure consistent

interpretation. Prior to writing this report the entire team of researchers met to develop the themes and structure for reporting.

## **2.4 Notes on reading the report**

There are a number of caveats to bear in mind when considering the research findings.

The context of the research should be borne in mind in that it was conducted during a period when the pressures on the NHS have been widely reported. Therefore, time and resource issues were likely to be top of mind for participants.

It is worth noting that the doctors who participated in this research 'opted in' to the process and actively responded to communication about the research saying that they were willing to participate. It could be that those who opted into the process are different in some way (in terms of their approach or attitudes) than the wider sample of doctors eligible to participate.

It is also important to note that qualitative research is not intended to be statistically reliable and, as such, does not permit conclusions to be drawn about the extent to which something is true for the wider population.

Throughout the report, quotes have been included to illustrate particular viewpoints. It is important to remember that the views expressed do not always represent the views of all doctors who attended. In general, however, quotes have been included to illustrate where there was particular strength of feeling about a topic.

### 3. Overall awareness and attitudes

#### ***Section summary***

- There is a general awareness of the broad principles of consent and the need for shared decision making, but the need to individualise the consent conversation, and the legal impetus to do so, is less top of mind. Awareness of the Montgomery ruling across the groups was low.
- The majority of participants expressed their willingness to practise in line with the General Medical Council (GMC) principles of consent and shared decision making - but some were more willing than others.
  - **Younger doctors** often displayed more natural support for shared decision making.
  - **Doctors who work in certain specialisms** (for example, mental health) where there is evidence to suggest that shared decision making impacts positively on the overall success/adherence to the treatment/procedure.
  - **Doctors who appeared automatically to adopt a patient centred approach** to their overall practice.
- All agreed that practice has become much less paternalistic and more patient-centred over the years. However, doctors also acknowledge that there are some areas of current good practice over which they lack clarity (for example, the role of written patient information; and the need for, and status of, signed consent).
- Formal training around consent appears 'patchy' during medical school. However, most concur that 'on the job' training and learning from colleagues is preferable, as it is less abstract and can be tailored to individual specialisms.

#### **3.1 Awareness of the key principles of consent and the GMC guidance**

When asked at the start of the discussions to summarise individually what they saw as the key principles of seeking and recording consent for investigations or treatment, most doctors spontaneously mentioned the following:

- Ensuring informed decision-making by clearly outlining choices, associated benefits and risks to patients.
- A shared decision.
- Not leading or influencing patients.
- Presuming capacity.

Whilst there was a broad understanding of these fundamental principles of consent, few had ever referred to the GMC's guidance on consent. Furthermore, across the groups there were fewer spontaneous mentions of specifically tailoring the information about benefits and risks to individual patients. Individualising the consent conversation only tended to emerge during the course of group discussions, often when doctors debated the validity of signed consent

Those doctors with the most detailed understanding of the GMC's guidance on consent appeared to have this knowledge often because they had responsibilities or roles in addition to their main job. For example, one doctor gave technical advice to the Parliamentary and Health Service Ombudsman and another was a trainer and a member of a defence organisation's Council. Others mentioned that they were prompted to review the guidance because of exams, a job interview or a patient complaint.

Awareness of the key principles of consent and shared decision making was most variable amongst GPs. For some GPs this was a less top of mind issue; those with lower levels of awareness only tended to think about consent in relation to minor procedures and intimate examinations.

*"I probably overlook it because I've been there for such a long time. When you formally come to do it, when I'm doing minor surgery...that's probably the only time I ever record it but most of the time I assume implied consent. I might be shocked in a minute what the proper guidance is." (GP, more than 10 years qualified, Stockport)*

### **Awareness of recent legal changes**

Only a minority of participants, again often those with additional responsibilities to their main job, were aware of recent legal changes and the Montgomery judgement<sup>3</sup> in particular. However, some of those who were aware expressed some concerns about the implications of this legal judgement.

*"...we're in a time-restricted environment with Montgomery case law and all of that about having to work out what the most important factors for that consent process are for that individual patient and then making sure that those are addressed. I kind of feel like it's a bit of a losing battle for doctors, you can't get it right every time for every patient." (Surgery, less than 10 years qualified, London)*

Others recognised that it upheld current GMC guidance:

*"In actual fact throughout they said we're [making] legal reference not to some new standard we're making up but to the GMC and the Royal*

---

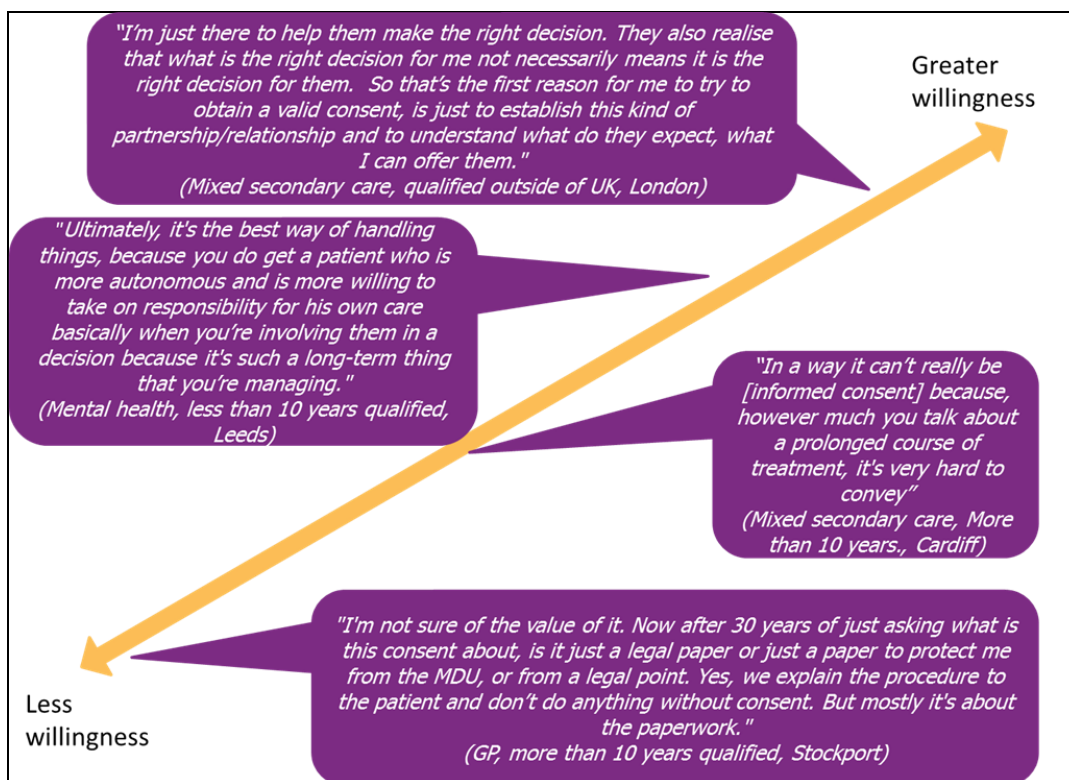
<sup>3</sup>The law on informed consent has changed following a Supreme Court judgment. Doctors must now ensure that patients are aware of any "material risks" involved in a proposed treatment, and of reasonable alternatives, following the judgment in the case *Montgomery v Lanarkshire Health Board*. This is a marked change to the previous "Bolam test", which asks whether a doctor's conduct would be supported by a responsible body of medical opinion.

*College of Obstetricians' guidance that existed at the time." (Psychiatrist, more than 10 years qualified, Edinburgh)*

### 3.2 Attitudes towards consent guidance

Whilst almost all participants stated a willingness to practise in line with GMC guidance on consent and shared decision making, some were more enthusiastic in their support than others. For some doctors, it was evident from the way they discussed the issues (the language used and the experiences that they shared) that they were fully committed to the principles and tried wherever possible to apply them (notwithstanding the challenges explored in Section 4).

However, for others the language used and the questions raised suggested that shared decision making was not as fully embedded into their way of working (either individually or organisationally) and it was more process-led, or driven by defensive practice (i.e. the desire to avoid any legal challenges influencing behaviour, often in a way which is perceived to be negative - further expounded in Section 4.3), rather than a heart-felt commitment. Figure 1, provides a selection of verbatim quotes from doctors that clearly illustrates this range of commitment and how it was expressed.



**Figure 1 – Range of commitment to shared decision making**

There are a range of factors that appear to have some influence (but cannot be used to predict) doctors' attitudes towards consent and shared decision making:

- **Age** - younger participants often displayed more natural support for shared decision making; some older doctors commented on how their younger counterparts had been better educated in consent and shared decision making.
- **Specialism** - doctors who work in specialisms (for example, mental health) where there is evidence to suggest that shared decision making impacts positively on the overall success/adherence to the treatment/procedure; appear more positive about the principles.
- **Attitudes to wider practice** - doctors who appeared automatically to adopt a patient centred approach to their overall practice had shared decision making embedded into their way of practising.

Regardless of the extent to which individual doctors supported the GMC principles of consent, doctors acknowledged an inherent tension in shared decision making - a lack of equilibrium in the patient/doctor relationship. They explained:

- That shared decision making does not bring with it shared responsibilities (the doctor is still seen as responsible for the overall outcome).
- That whilst the patient has control over what happens to their body, they do not have the doctor's level of expertise or experience of the procedures/treatments on offer.

*"That's a conflict because medicine is becoming more open and certainly, yes, people don't want us to behave or practice paternalistic medicine where you have the choice, you make the decision but...Whose fault is it if things go wrong, exactly?" (Mixed secondary care, qualified outside of UK, London)*

Some doctors also commented that they felt that consent and shared decision making was being used as a means to deter NHS patients from electing to have treatment (by outlining risks at length) and so conserving resources.

*"It's funny because sometimes when you hear patients coming in, they come in for a procedure and you can see that this consent is actually being used to deter them from actually having the operation. It was almost like used as a weapon really to try and dissuade patients." (GP, more than 10 years qualified, Stockport)*

However, others disagreed and felt that it was working well if patients were not having expensive treatment that did not benefit them or made only a marginal difference.

*"Over prescribing might lessen (and therefore iatrogenic disease) if doctors get used to giving more facts about their proposed therapies – and patients get used to asking for that." (Psychiatry, more than 10 years qualified, Edinburgh)*

### 3.3 Current practice

There was some recognition that current practice does not always meet the ideal and some uncertainty about whether their own practice was in line with guidance in some areas. The following areas, in particular, were apparent:

- **Use of written information** - some doctors were unclear about the role of, and how much they should rely on, written information for patients.

*"A patient information leaflet, would that give you some manner of protection, as it were, that you've given them this for them to read? Is that sharing or is that not... I don't know?" (GP, more than 10 years qualified, Stockport)*

*"With medications, some of us think we're covered because the pharmacy who dispense the medication enclose a leaflet with patient information and dozens of small print about side effects, which I don't think many of us routinely go through all the side effects." (Psychiatrist, more than 10 years qualified, Edinburgh)*

- **Seeking meaningful consent at an appropriate time** - amongst doctors working in secondary care there was some debate about the appropriate time to seek consent and they gave examples of it happening too late in the patient journey, for example times when the patient is most vulnerable i.e. just before the treatment or procedure. Some surgeons mentioned working in hospitals where, until recently, it was commonplace for a consent form to be completed on the day of surgery rather than in advance. Some also mentioned that the consent process was being done very poorly at times with some patients indicating that they haven't been involved in decisions about their treatment, immediately before their procedure.

*"To go back to the time of consent. In an emergency situation you're pressurised, but I think actually to take consent when a person is in one of those horrible open backed gowns, in a bed, with all their clothes off, is not right. Because are they going to say 'hang on, I'm off, give me my clothes back, I really don't want this'? No they're not. Whereas if you had done it beforehand, if they turn up, they've had time to think about it, look at whatever information you've given, and I think it is often left until the last minute." (Mixed Secondary Care, more than 10 years qualified, Cardiff)*

- **Type of procedure/treatment** - some mentioned that they would spend more time on shared decision making if the treatment was non-standard or likely to have a big impact on the patient than if it was something more standard. Less risky treatments received less attention.

*"I think, if it's something that is quite a big investigation with many risks involved, or is a very different treatment to what the patient is already on, then you try and seek consent much more than if it's something that's run of the mill or isn't really different to what the patient's already had. Because I think you're much more likely to assume that the consent is there, so it's kind of done more off hand than if it's something very different that could significantly change their life." (Mental health, less than 10 years qualified, Leeds)*

- **The role of signed consent** - some doctors initially conflated consent with form-signing rather than seeing it as a broader process, starting with a discussion. There is also some confusion around the validity of signed consent and the extent to which it is upheld by the law. Several doctors also queried at what point they should be seeking signed (as opposed to verbal) consent.
- **Clues from language** - although not raised by doctors themselves, the language within current practice appears contradictory to the fundamental principles of consent and shared decision making. Doctors in secondary care settings very frequently refer to 'consenting a patient', suggesting that the patient has an entirely passive role in the process.

### 3.4 Awareness of changing practice

Some participants reflected that their own, individual practice in this area has changed over recent years, prompted by changes in the prevailing culture (and sometimes the legal context). Some of the GPs mentioned noticing more discussion and recording of risk in secondary care consultations than they have seen previously.

*"I say, which perhaps I wasn't in early years of my consultancy, but I point blank say that I am not the one who will make a decision, it's your choice, my job is to give you the options, you have to make the decision. I can help you but I will not make decision and I am absolutely up front about it, that is my role now." (Mixed secondary care, qualified outside of UK, London)*

There was widespread reference to surgeons having a reputation for being more paternalistic than other types of doctors. Participating surgeons, however, drew the distinction between the past when they had to "sell" themselves and their expertise "like a second hand car salesman", to a patient to instil confidence. Now they tend to feel the approach is much more one where the patient is seen as a partner in the discussion.

*"But I think it's changed over my 35 more years in the trade, is that we are conscious of the bias much more than we were and we are less*



*paternalistic and we are more willing to accept the patient's point of view and not push and to actually have a dialogue about it." (Surgery, more than 10 years qualified, Birmingham)*

Other participants also reflected that they feel that there has been a generational change and that younger doctors are more cognisant of and open to shared decision making.

### **3.5 Experience of relevant training**

#### ***Formal training for medical students***

There is a general consensus that formal training is 'patchy' in relation to consent and shared decision making. Doctors who had recently qualified often mentioned receiving training in ethics (of which they see consent and capacity as a key part). Doctors with less than 10 years' experience in Belfast reported receiving training on consent and capacity provided by the GMC to medical school students in Belfast.

However, there was a sense that training within ethics is variable, with some coverage of consent and shared decision making, but not necessarily formalised into a specific module. Some had experienced specific sessions on consent involving role play, but others had not.

*"It's amazing how little time is dedicated to something so important that we're expected to do to a high standard, and that's important for the patients because they're having these interventions. The amount of time dedicated to it in Medical School or subsequent training is minimal really." (Surgery, less than 10 years qualified, London)*

*"Essentially, consent is negotiation and people who work for business or companies, they will have enormous amounts of training on negotiation and so on, because it affects their outcomes of what they do; and in our case it does the same but we're just thrown into it." (Surgery, less than 10 years qualified, London)*

Some more senior doctors commented that training in this area for medical students has changed since they qualified, but assumed that it was more of a 'box ticking exercise' rather than fully exploring the nuances of taking consent. They felt that it was important for any training to be specific to the specialty in which the doctor was working.

#### ***Formal training for qualified doctors***

In terms of the training available during the course of their practice, there were some examples given relating to consent, including the following:

- Online module on the deprivation of liberty.
- Training on seeking consent for organ donation.

- Training provided by a CCG on assessing capacity to consent.
- Training provided by the defence unions.

However, some participants felt that the formal training they received around consent and shared decision making was minimal.

### ***'On the job' training***

The majority of participants explained that much of their training around consent and shared decision making was 'on the job'; learning from senior colleagues and peers. Most believed that the practice of consent and shared decision needs to be tailored to the specialism they work in and the specific procedures and treatments involved. Therefore, this 'on the job' training was often regarded as more relevant than formal, or abstract training.

*"Most of your knowledge from consenting is actually watching your seniors consent and picking out bits that they did well and trying to piece that together in your work to find out what works for you, and what works for the patient ultimately." (Mixed secondary care, less than 10 years qualified, Belfast)*

## 4. Key challenges associated with meeting the guidance

### ***Section summary***

- At a systemic/organisational level there are numerous challenges associated with being able to meet the guidance on consent and shared decision making - many of them driven by the lack of resources within the NHS. Most notably doctors, working in many different specialisms, reported that individualising the consent conversation takes time that they (and the NHS) cannot afford.
- Other key challenges include, but are not limited to:
  - Difficulties with assessing the capacity of a patient – particularly when the patient has fluctuating capacity, and/or when the patient is making a seemingly irrational decision.
  - Being able to understand what is important to individual patients; the range of patient attitudes and expectations.
  - Being able to provide complex information to patients in a way that they can understand.
  - Lack of up to date knowledge of some procedures and treatments – and their risks and benefits - amongst some doctors.
  - Dealing with family who may have different views to the patient and different expectations of the doctor.
  - Both patient and doctors adapting to the changing patient-doctor relationship.

Further detail on each of the challenges is provided below, categorised at the level at which they occur (systemic/organisational, individual patient or individual doctor).

### 4.1 Systemic/organisational level

#### ***Limited time with patients***

Throughout discussions participants referred to the continual and rising pressure on resources within the NHS. Undoubtedly the overriding challenge associated with meeting the guidance is how to spend more time understanding the increasingly complex needs and preferences of patients (with increasingly high expectations of the health service) when less resource is available to do this.

Time was mentioned as a key challenge in all groups. However, it was particularly an issue for:

- **GPs** because of the volume of patients that they see and the impact of spending longer with each patient on their ability to see their full patient list.
  - They were concerned that more time spent focussed on consent and shared decision making would mean that there would be less time for the consultations that really need attention.

- **Anaesthetists** because their role means that they only see the patient for a limited time, immediately before the procedure and so they have little time to build up a relationship.
  - An anaesthetist who had previously been working in Italy mentioned that in practice there she routinely saw women at their ante-natal classes and other appointments to discuss benefits and risks of epidurals etc. so that they had information in advance and could make an informed choice if necessary. She had suggested this when she came to practise in the UK, but was told that there were insufficient resources.
- Those working in **emergency care** are already stretched and have multiple challenges to consider. Some mentioned that they do not conduct the consent conversation as well as they would like:

*"I think there has to be an acknowledgement that this practice, I think it's very good for the patient, it gets them very involved and very conscious about what kind of treatment or procedure they're going to get....if you get a patient with a lot of questions that can take a whole hour, if not a second visit as you said. In intensive care on a Saturday evening with one trainee engaged in something else and myself dealing with the family and another million things happening, there's simply no room for that." (Mixed secondary care, qualified outside of UK, London)*

There was a perception, that seeking consent and shared decision making may be somewhat easier in **elective surgery and mental health** as patients have a number of appointments, meaning consent can be discussed in stages, allowing patients' knowledge to be built up gradually. However, some concerns were raised by doctors working in these areas too:

- Some surgeons raised that in their Trusts, the number of times doctors see a patient is being rationed and this can have a detrimental impact on this process. Furthermore, surgeons don't always see patients post-op and cannot learn what patients are surprised by or have misunderstood to help them better work with new patients having the same procedure.
- Resource pressures also led to more delegation of the consent process within surgery. There were concerns associated with junior staff having insufficient knowledge to discuss consent with patients adequately for the procedure in question. It was widely felt the doctor needs to be able to perform the surgery and to have seen the range of outcomes to be able to seek consent effectively.
- Time and resources was a less prevalent issue amongst participating mental health practitioners, but this may have been because of the specific settings in which the doctors were working.

### ***Continuity of doctor patient relationship***

Some doctors raised the point that NHS structures and processes make adhering to good practice more challenging i.e. ideally one person would take a patient through a

journey of consent but NHS contracts and the working time directive can make continuity of care impossible.

*"I think the nature of our working patterns since ...the new deal, which is going back quite some time, means that you're not consistently on the ward with the same patients the whole time, you've got many, many more times the amount of patients when you're on nights and weekends, evenings and you don't have the regular doctors, so there might be considerably less continuity for the patients on your home ward or whatever it might be, in inpatient settings anyway." (Mental health, less than 10 years qualified, Leeds)*

*"But in the modern NHS certainly, different clinicians see different patients at different points through their journey, and consent is sort of a process over time. So different people give different information in different ways with different risks, thinking of different alternative treatment at different points in the process." (Surgery, less than 10 years qualified, London)*

Likewise GPs raised the issue of patients not having a named GP and the difficulties associated with patients being able to get an appointment. This results in patients visiting several different GPs and makes it difficult for GPs to have follow-up conversations regarding a consent conversation they may have started.

*"So it may be that you do have full consent for something in one treatment but the patient might struggle to get another appointment straight away because there's so much pressure on people coming in. So, yes, I think for simple straightforward things you can do it in 10 minutes, but for other things you need to bring people back and maintaining that continuity can be difficult." (GP, less than 10 years qualified, Edinburgh)*

### ***Time available for training***

Doctors also mentioned that pressure on resources means that there is less time for thorough on-the-job training, especially for softer skills like communication and consent.

GPs also raised the issue of not having protected learning time for continual professional development.

### ***Availability (funding) of treatments***

Some participants also felt that shared decision making was an ideal but does not work in practice because of limited budgets. If a patient and doctor agree on a specific treatment, it may not be funded by the CCG or approved by NICE and, therefore, it may not be available.

*"I've had some of my patients where we agree that they need treatment but the treatment isn't actually covered by the health board, then you've got to go through the process of applying." (Psychiatrist, more than 10 years qualified, Edinburgh)*

### **Recording information**

Many doctors were unsure of what should be recorded regarding consent. They felt that practices were variable, with some doctors recording significantly more detail about patient discussions than others.

Some doctors also highlighted issues with inconsistent systems for recording and looking up information.

## **4.2 Individual patient level**

### **Assessing capacity**

Doctors were aware that there is a presumption of capacity. They explained that it was relatively straightforward to ascertain where a patient very clearly did or did not have capacity. The challenges arose from the spectrum of cases in between. Difficulties associated with assessing capacity for more borderline cases were raised across all the groups, with the main issues raised being:

- Lack of time to assess capacity.
- Lack of understanding of the history of the patient.
- Finding interpreters for patients who cannot speak English.
- Judging the impact of physical pain and mental pain (grief, shock etc.) on a patient's ability to take in and process information.
- Ascertaining the wishes of someone with fluctuating capacity.
- Dealing with patients who are making a seemingly irrational decision.

*"I think it's a profession that a lot of people go into to care for other people and to want to help other people in one way or another and it's a bit paralysing when you are in front of someone which you have an idea of what can be good for that person and you feel they're making a decision which you feel is unwise." (Mental health, less than 10 years qualified, Leeds)*

There were some interesting reflections on how the assessment of capacity works in practice from various perspectives:

- Some doctors specialising in mental health felt that they were often called in to conduct capacity assessments as a result of another doctor not getting the desired outcome i.e. the patient not doing what the doctor thinks they should. This perception was confirmed by doctors in some other specialisms.

*"Yes, if they come up with the same decision as you, you think yes, they've got capacity. If they want to take an unwise decision you think I'm not sure they have capacity." (Mixed secondary care, more than 10 years qualified, Cardiff)*

- Doctors not specialising in mental health acknowledged that, in theory, they could call on experts in the field but indicated that they always tried to assume capacity because of the administrative burden of not doing so – who they would need to consult, what they would need to do and to document.
- There is some recognition that it can be easier to assess capacity in a mental health setting rather than in an acute setting.

### ***Patients' inability to understand and assess risk***

Doctors across all groups raised the issue that not all patients with capacity were able to understand odds or percentages and assess risk. This inability to understand risk may be linked to a patient's general understanding; or could be the result of them being in a very stressful situation.

*"It's kind of an understanding of risk, isn't it, and people aren't good at it. So if you're told you have a one in 80 million chance of winning the lottery, you think it will be you so, of course, you also think it will be you that dies from a perforated bowel. So that's a real problem, when you start to use numbers, the logic might go out the window." (Mental health, less than 10 years qualified, Leeds)*

### ***Dealing with different attitudes/expectations and ascertaining what is important to individual patients***

There were numerous challenges associated with tailoring information to individual patients and ensuring that doctors take note of individual values and preferences. Doctors felt strongly that this was extremely difficult to do in the time that they may have with a patient. This is further compounded in some specialisms where doctors may only get to see the patient once.

*"But what was fascinating, there's always the questions at the end and there was an older lady come up at the end who said she'd had tamoxifen for breast cancer and, whilst she'd got a good result, she was crushed with it, because she'd been a fantastic singer and she loved singing and she hadn't been told this will affect your vocal chords. Now, maybe she would have had the treatment any way if it had been explained to her but she was terribly disappointed in this. Now, how do you get there, how does a breast surgeon have enough knowledge of somebody to know what would or wouldn't... because that wouldn't bother me but it bothered her. And the example I gave when I was making a very similar submission was, Freddy Mercury never got his*

*teeth fixed, presumably he would have got a better cosmetic result but, to him, any risk, even 0.1% of a change in his vocal thing was completely unacceptable. Now maybe he'd tell you that right away but you need to know, you're right, this statement about wants or needs [Part 1: Principles, paragraph 2c] predisposes knowing enough about them to know their desires and choices." (Psychiatrist, more than 10 years qualified, Edinburgh)*

However, even with sufficient time, doctors felt that it was sometimes difficult to uncover what actually matters to individual patients as patients themselves did not always engage in the process of shared decision making. Furthermore, doctors reflected that patients can lack insight into their own need for treatment. They may have capacity to decide but may lack the insight to see the need for treatment.

*"I think some patients actually need more encouragement to hold up their end of the consent process. Some of them just sit back, they understand what you're saying and they're happy to go with the flow. That's okay but sometimes you need to explore it and encourage them to engage with you a bit more and say 'what do you actually think about this?', 'what's your thoughts about it?' and that sort of brings them up, maybe it prompts them to think in a bit more detail to what they're actually committing themselves to." (Mixed secondary care, less than 10 year experience, Belfast)*

Some doctors raised the challenge of discussing risks of treatment which were very serious but also very unlikely, in a limited time, without unduly frightening the patient. Some gave instances of patients who actively did not want to be told of uncommon, severe risks, citing complaints about scare-mongering or being asked to make a decision that they do not feel qualified to make.

*"[My patient complained] 'this doctor painted quite a dark picture of what can happen to a perfectly healthy woman'. So obviously after this I thought what should I do next? how much is enough? how much is not enough?" (Mixed secondary care, qualified outside of UK, London)*

Some also reflected that patients who did not want information, then later complained about not being told of risks when something has gone wrong. Other instances were given of patients being told about possible pain at a consultation and then downplaying it because they do not want to think about it at the time, only to complain about it afterwards.

### ***Dealing with language/literacy issues***

Numerous practical issues were raised with seeking consent and shared decision making with patients who cannot speak English. Whilst a number of doctors spoke of



their preference for using face to face interpreters, they also acknowledged that this was time consuming and costly to arrange. The technology (Language Line) was used but it was also criticised for being unreliable and impersonal. Therefore some participants had resorted to using facilities like Google Translate or calling on another doctor to translate.

*"Where getting hold of Language Line, texting them, getting hold of an interpreter takes a lot of time, and it's expensive. So we've got members of staff who speak certain languages and we'll get them to come along, and that works for a number of patients, not all of them." (Mixed secondary care, more than 10 years qualified, Cardiff)*

Establishing the capacity and seeking consent from a patient who cannot speak English was felt to be particularly challenging. Senior psychiatrists believe that GMC guidance on consent needed to be more explicit in this area:

*"We've had several patients in hospital and it's several days before they've made their point. It's just not possible to get that consent unless you and the patient share a common language or you have a competent translator. People can often be in hospital for quite some period of time and have some degree of intervention when there's no common language at all. In the A&E situation maybe that's fair enough, somebody comes in and their leg's hanging off, then you do what you need to do, but the idea that the person cannot possibly have given consent because nobody can speak their language and they can't speak English, it seems on the face of it very obvious but in the guidance and the resource it should say very explicitly." (Psychiatrist, more than 10 years qualified, Edinburgh)*

Many doctors spoke about the problems associated with using family members in an interpreter role because of the lack of any alternative. Most notably, that they lacked confidence in the accuracy of the translation and/or that, because they could not understand what was being said, they were unable to ascertain if the patient was being influenced by the family member. For example, they could not be sure of which parts of the conversation were being translated and the family member could selectively translate or add in their own interpretation of what the doctor said.

### ***Dealing with family***

Some found it difficult to know whether the patient was making the decision about their own treatment or if they were being unduly influenced by family.

*"I think there's a very fine line between a patient making a decision for themselves and a patient making a decision based on what their family has told them, or if their family's saying 'no, you need to do this, so do*

*this', and then you can see people saying 'yes, I'll do it.'" (Mental health, less than 10 years qualified, Leeds)*

Many instances were cited of the family criticising a doctor for seemingly not doing enough for their family member when in fact the patient had refused treatment or a specific procedure. Particular issues were noted with advance refusal of treatment and family views differing from those of the patient.

Examples were also given of patients being strongly influenced by family because of the cultural beliefs of their communities, for example:

- Some communities refusing medication for epilepsy because they believe it is a spiritual issue rather than medical.
- Some communities (e.g. Somalian) who believe that there should not be any medical intervention in childbirth so they refuse c-sections and pain relief.

### **4.3 Individual doctor level**

#### ***Knowledge and expertise***

Senior doctors reported that taking consent is an area of practice they have become progressively better at, the longer and more frequently they have explained a procedure. Over time, they can anticipate the questions that are likely to come up and the best way to answer them. They spoke of having developed resources and diagrams that explain things in ways patients can generally understand.

However, some doctors still raised the point that they often do not have sufficient expertise to be able to talk authoritatively about risks and benefits of treatment, either because they are generalist GPs or because there are rapid advancements that are difficult to keep up with.

*"Sometimes we can't keep pace with all the changes in medicine, so people will come up with different expectations or reading on the internet or based on different treatments which might be evidence based or probably not evidence based. Then they'll certainly demand answers from you and you might not have a clue what they're talking about." (Mixed secondary care, qualified outside of UK, London)*

Some also highlighted the growing complexity of explaining risks. For example, much surgery now is at the margins of clinical need – surgery used to be much more a life and death thing, but now the benefits are often smaller / more at the margins but all surgery still has a degree of risk. This makes it even harder for patients to weigh things up.

***Knowing if a patient has understood the information provided***

Doctors highlighted that whilst they can simplify the information and even try and have several conversations over a period of time, they find it difficult to know with any degree of certainty whether the patient has thoroughly understood all the ramifications of a treatment or procedure.

***Defensive practice/fear of litigation***

Some examples were given of increasingly defensive practices, for instance doctors listing out all of the possible risks to patients because they are unsure of which to focus on and fearful of not mentioning a risk, however small, in case of later challenges or repercussions.

*"There was so many complaints about information or not enough information or wrong information and not involvement in decisions, that we modified our practice and became very defensive." (Mixed secondary care, qualified outside of UK, London)*

*"I think that medico legally they want you to record things... even if they're very rare, if they're very, very significant. So there's like a mismatch between... common and not severe should be talked about but it's actually the rare but important, isn't it?" (GP, more than 10 years qualified, Stockport)*

***Changing relationship between patients and doctors***

There is a strong feeling that the relationship between doctors and patients is changing and that doctors are no longer seen as the authoritative figures that they once were. Some felt that the focus on shared decision making could be disempowering for doctors as it did not recognise their expertise. Some more junior doctors found this particularly challenging as they felt that the discussions around consent could make them seem inexperienced and indecisive with patients.

*"I think we're slowly moving from a figure where the physician was clearly patronising and paternalistic and not very approachable to the other end where the physician is just somebody not very respectable, who is not even worth looking at because we always have Google who is going to give us a better answer." (Mixed secondary care, qualified outside of UK, London)*

***Unconscious bias***

A number of the participants were quick to recognise the possible influence of unconscious bias, for example, where surgeons have an underlying desire to operate, regardless of patients' views.

*"We've had studies that have randomised patients to chemotherapy first versus surgery first and we know that, if the patients see the surgeons, the surgeons are certainly biased just to give them surgery first and, for those trials to succeed, they've got to get some kind of independent view on what's being offered. There is no clear incentive in the NHS with our waiting lists and our various troubles to operate but we still can't help being who we are." (Surgery, more than 10 years qualified, Birmingham)*

Doctors working in other specialisms also recognised that they may unconsciously nuance the consent conversation by their own opinion of what is best for the patient and that it is difficult to know how much this may influence a patient's decision.

*"Most people will go with what you want and the difficulty is being aware of who you are as a practitioner as well. Because you need to be aware that, although you're formalising the consent process, you do all this when you tell them the information, they sign the form, you can still from your preconceptions talk somebody in or out of an operation no matter what they choose sometimes. And it's, again, being aware of yourself when you're consenting people, that you are trying to be as impartial as you can be because you can definitely influence the consent." (Mixed secondary care, less than 10 years qualified, Belfast)*

*"Because like my colleague mentioned, there are certain things that we know is best for the patient but they may not necessarily be the patient's choice and it's just trying to clarify whether the patient's confused or not getting what we're saying, and sometimes I might influence the way we push across, you don't know." (Psychiatry, less than 10 years qualified, Leeds)*

### **Experience of different cultures**

Several doctors who had qualified outside of the UK but within the EU mentioned that they had been surprised by differences in regulations and guidance. They described the systems in Spain and Italy as being more 'medico-legally driven' with the need for written consent for many more procedures and treatment than in the UK. It was mentioned that for consent relating to children there is a need for a signature from two legal guardians (typically the mother and father) before treatment can begin. This lack of a strict formal structure created some anxiety for these doctors who felt more vulnerable as a result.

Other doctors raised the issue of working with team members who have qualified outside of the UK and who are used to working in a more paternalistic system.

*"Where we struggle is with overseas doctors because,...in some parts of the world still the doctor is the doctor, 'I'm the doctor, I know*

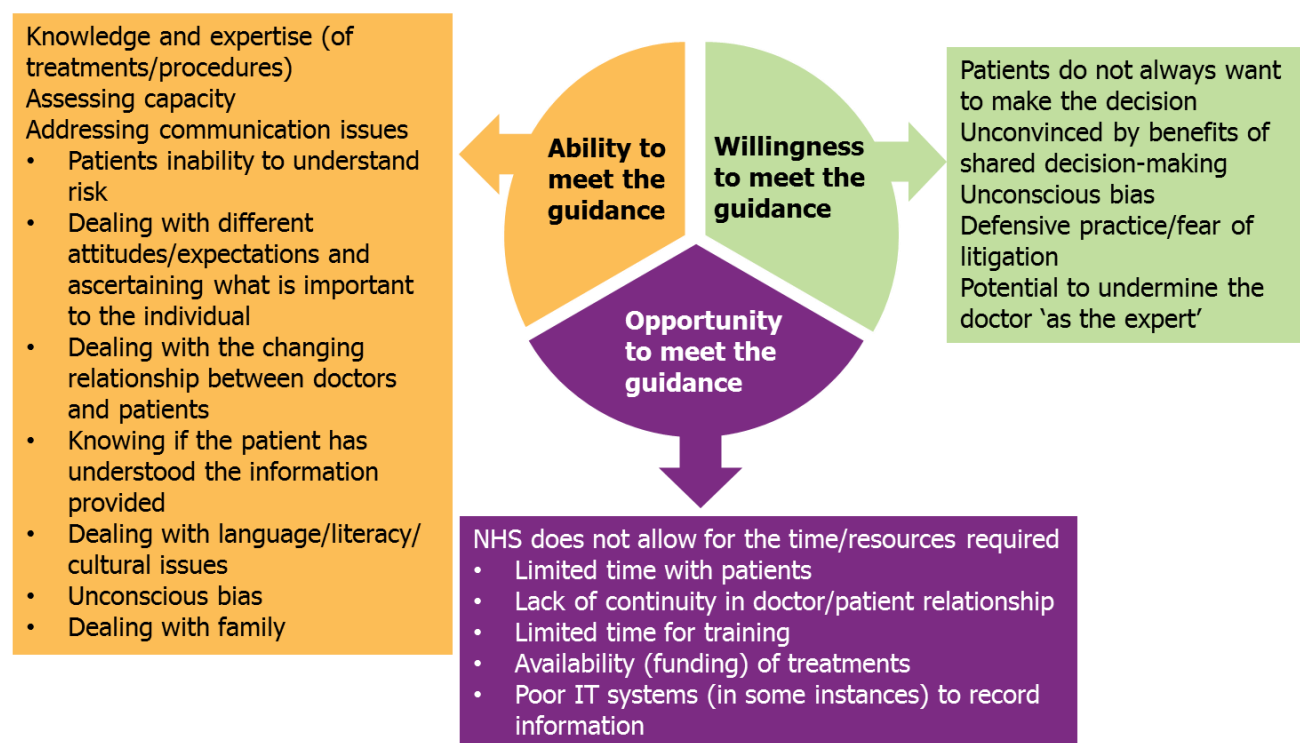
*better'....When I tell them you have to speak to the patient, you have to listen to the patient and they're like 'no, I just have to do my job'. "*  
*(Mixed secondary care, qualified outside of UK, London)*

Some of the participants at the group who qualified outside of the UK did appear to have rather more paternalistic attitudes than other participants (although clearly this research is qualitative and this cannot be relied upon as being true of the wider population).

#### 4.4 Grouping the key challenges: ability, willingness and opportunity

As well as looking at the key challenges in terms of where they occur (organisational level, individual patient level and individual doctor level) it is also possible to group the challenges by ability to meet the guidance, willingness to meet the guidance and opportunity to meet the guidance. See Figure 2 below.

Reframing the challenges in this way helps inform how these challenges could be addressed. See section 8.



**Figure 2 – Challenges mapped to core behaviours**

## 5. Examples of good practice in consent and shared decision making

### ***Section summary***

Doctors were able to talk about a range of examples of relating to their practice which they believed helped them deal with the challenges of consent and shared decision making. These ranged from individual examples, such as ensuring that they assess capacity at a time of day when the patient was most likely thought to have capacity, through to examples of the team working together to ensure that the patient has an information pack/leaflet sent out with their first appointment card so they can read and come to their appointment prepared with questions.

There has been no formal evaluation of these examples and so it should be noted that they are considered good practice only from the perspective of the interviewee(s) who outlined them as such.

The following were mentioned as ways of dealing with some of the challenges identified in Section 4.

### ***As an individual doctor***

Individual doctors gave the following examples of how they deal with some of the challenges within their own practice:

Encouraging patients to 'talk back' about what they understand of their treatment - so that the professional knows that their patients have taken the information on board. This practice was widely referred to in Scotland in particular.

Working with patients by giving them the chance to reflect and return for another appointment.

Assessing capacity at a time of day when the patient is more likely to have capacity to consent.

GPs allowing 20 minutes per appointment where necessary i.e. to perform minor procedures (such as contraceptive implants, soft tissue or joint injections), more vulnerable patients.

Bringing former patients into a consultation to talk to new patients to help them understand what to expect from a procedure.

Setting up a website which hosts patient information about particular procedures they conduct.

Bringing risk, odds and percentages to life/making them meaningful to the patient e.g. using the equivalence with a size of a city or a town or a football stadium to explain "1 in a 1000" type odds.

***As a team***

Often the examples of best practice involved the wider team:

Reviewing of complaints relating to consent and shared decision making within the specialty to ensure that they learn from where things have gone wrong.
Building on good practice already embedded into training - for example the Calgary Cambridge framework mentioned as part of GP training on shared decision making (Stockport group.)
<p>The availability of standardised resources (information leaflets, videos, templates) for seeking and recording consent.</p> <ul style="list-style-type: none"> <li>• There were a number of examples of tailored information being produced for patients on risks and benefits of treatments or procedures. These tended to be produced on the initiative of an individual within a specific specialty and so were used by some teams and not others.</li> <li>• One doctor mentioned a leaflet that they gave out to patients and relatives in ICU in Spain which had a list of possible procedures that they may have to do to save the patient's life and asked for advance consent in case of an emergency.</li> <li>• A private dental surgery was mentioned that had developed videos for all the different procedures that show the process and explain the risks and benefits.</li> <li>• One Trust asked prospective patients to watch a dvd on joint replacement surgery.</li> </ul>
Using specialist nurses in out-patient clinics who can respond to patient questions after or between SHO appointments, which are very time limited.
Making sure the patient has an information pack/leaflet sent out with their first appointment card so they can read and come prepared with questions.
Multi-disciplinary team meetings (MDTs) are regarded as best practice to ensure that individuals hear different perspectives on the consent process; keep up to date with the latest practice on operations; hear about risks of drugs etc. Some reflect that working in teams can help reduce the risk of unconscious bias.
A junior doctor felt that being allowed to witness senior colleagues going through the consent process helped him to learn how to put things and how to deal with patients and their relatives better, which are difficult to learn in formal lectures during training.
Recording consent discussions for training purposes.

## 6. Sources of support and guidance

### **Section summary**

- Few doctors have detailed knowledge of, or see a particular need to refer to, the GMC's guidance on consent and shared decision making. Those most familiar with GMC guidance often had additional roles aside from their main job.
  - Instead doctors turned to their colleagues and the organisation they work for, for support and guidance.
- Doctors mentioned having sought situation-specific advice and support from external organisations, namely:
  - Royal Colleges.
  - Medical Defence Unions.
  - The BMA.
  - NICE.
  - Third sector organisations for patient information.
  - Local government sources.

### **6.1 Response to GMC existing guidance**

Few were aware of the *detail* of the GMC's guidance. If they were aware, this tended to have been prompted by attendance of the groups or because of a role or commitment that they had in addition to practising as a doctor. Some had been prompted to review the guidance because of a job interview or a patient complaint. There is a sense that such guidance sits on the shelf until needed – it is not something to refer to without reason.

*"Last time I looked at it was when I was a trainee and, since then, you get a lot of updates and there was a stage, where probably similar, I was interested in all the case law and things around it. But I haven't actually picked up and opened the guidance on it for at least 10 years."*  
(Psychiatrist, more than 10 years qualified, Edinburgh)

### **6.2 Response to alternative sources of support / guidance**

Most doctors would not naturally turn to the GMC guidance or resources if they had a query about consent issues. They were more likely to speak to colleagues or contact their Royal College, defence organisation, NICE or the BMA. This was often driven by the need for situation specific guidance. Scottish doctors also referred to NHS Scotland and the Mental Health Commission in Scotland as being better placed to offer country specific advice.

*"I think the GMC, for me, should be the short A5, 70 to 100 points, written in that sort of diamond style 'you should do this and minimum proof of consent is this', and that should be the GMC's role. Then the colleges and the Mental Health Commission here in Scotland can maybe*



*do the practice guides and the case presentations and the capacity toolkits and all that type of thing. I think the GMC should be like the Ten Commandments and somebody else can do the catechism.” (Psychiatrist, more than 10 years qualified, Edinburgh)*

*“I use RCOG guidelines when it comes to consent and our college was ahead of the game in the consent front (RCOG guideline on consenting for hysteroscopy). Also I use NICE guidelines.” (Surgery, more than 10 years qualified, Birmingham)*

Doctors explained that the medical defence unions and the BMA offered more personalised, situation specific guidance via helplines. Some felt that the GMC could also consider offering telephone or online support, where doctors could anonymously discuss issues on consent. However, others thought that personalised styles of guidance sat uncomfortably with the GMC’s regulatory role

*“I’m afraid that to some doctors the GMC appear as a threat to their livelihood, so they’d much rather source guidance from the MDU and the like who are likely to fight to preserve it.” (Psychiatry, less than 10 years qualified, Leeds)*

In addition to the aforementioned sources of guidance on consent and shared decision making, the following specific resources on assessing capacity were mentioned as being helpful:

- Paramedic resources (a one page, green sheet with key questions to assess quickly).
- Template for assessing capacity on the Manchester.gov.uk website.

Within the group discussions doctors also mentioned using information for patients from the following:

- Literature on advance refusal from 'Compassion in dying.'
- Macmillan Cancer Support.
- Resources for mothers on consent produced by the Obstetrics Anaesthetists Association, which are translated into different languages and at different levels of complexity depending on capacity and whether they are in pain etc.

## 7. Detailed review of the GMC guidance

### **Section summary**

Doctors who took a more detailed look at the guidance on consent and shared decision making were broadly positive about it, although some suggested there was opportunity to make it more 'reader friendly'.

Although not disagreeing with the content, they all raised the point that the guidance sets out a 'gold standard' that is not always achievable in practice due to the time constraints they work under.

The main area where they called for more information was in the section on Capacity Issues, including:

- Establishing capacity of patients who do not speak English.
- Guidance on when to seek a second opinion.
- Greater focus on the need to constantly re-evaluate capacity.
- How to deal with potential disagreements within families.
- Links to organisations that may be able to offer help with capacity issues.

Within all sections they highlighted several points that they believed would benefit from clarification/expansion.

### **7.1 Initial reactions**

When asked to review the key principles of the GMC guidance during the group discussions, the response was largely positive.

- When shown the summary, two groups picked up on the acknowledgement that different patients may want more or less information or involvement.
- Those working in mental health specifically welcomed the GMC principle that states that '*they [the patient] also have the right to accept or refuse an option for a reason that may seem irrational to the doctors, or for no reason at all*'. They believe it is important that this is a central principle as it can easily get lost or distorted in practice.

*"I like this phrasing, individual patients may want more or less information or involvement in making decisions depending on their circumstances or wishes. So it recognises that they... and I think that's very important that the GMC recognise that because, as you say, everyone's different, all patients are different and some do not want to be told all the possible scenarios, whereas some do, but it's difficult to know which ones." (GP, more than 10 years qualified, Stockport)*

The online bulletin board gave doctors the opportunity to read the guidance in full in their own time and give their considered response. The overall content of the detailed guidance was well received, with the electronic version was considered particularly

easy to use. However, all felt that the guidance did not take into account the time pressures they were under, underlining a key systemic challenge.

## 7.2 Structure and layout

Some doctors called for the written guidance to be more concise and presented in a more interesting way; they felt that a list of paragraphs and bullet points made it quite laborious to read. Some suggested that key points should be highlighted and repetition of information (at different points) avoided.

*"Is there possibly a way to make this more doctor friendly (after all we have patient friendly approaches and doctors are human beings as well) as I struggled with the text and it came across as more appropriately structured as a legal document. Breaking the information into section summaries and the use of colour marks identifying helpful areas with bite size information rather than lengthy paragraphs would make life bearable for a busy medic." (Psychiatry, less than 10 years qualified, Leeds)*

## 7.3 Missing elements

In terms of what was missing from the overall guidance, several doctors called for the following:

- Greater emphasis on the patients' responsibilities.
- Links from the main guidance to case law.
- Links from the guidance to organisations that may be able to advise on capacity issues.
- Greater focus on the need to constantly re-evaluate capacity and consent because it changes.
- More guidance on assessing the capacity of patients who do not speak English.
- More guidance on how to deal with potential disagreements between patients and their families.

## 7.4 Review of specific sections

Participants in the online bulletin board were asked to give feedback on specific sections of the guidance. Appendix 2 gives a summary of the bulletin board comments by paragraph; however, below are some of the key themes that emerged relating to each section.

- **Sharing information and discussing treatment options (paragraphs 7-26)**
  - These initial sections were regarded as clear, well written and patient centred. As with much of the guidance, doctors found little to criticise other than the fact that they do not feel that they have the time always to put the guidance into practice. They felt that the paragraphs set out the gold standards for practice, which is not always achievable.

*"Overall a good emphasis on patient centred care. Like others, I think the real difficulty comes in putting all of this into practice given resource and time limitations. Whilst it is clear from the guidance that consent should be tailored to an individual's needs, realistically I think most doctors would go for a blanket approach to cover the majority of risks in order to be safe and avoid making assumptions on behalf of patients." (Surgery, less than 10 years qualified, London)*

- There was suggestion that 'want or need' in paragraph 9 warranted more explanation otherwise doctors may resort to telling the patient everything, which had a further impact on time.
- Paragraphs 13-17 were thought to offer particularly useful guidance about times when patients with capacity do not want to know the details of their condition/treatment.
- There was some suggestion that using 'must' rather than 'should' needed to be reviewed in certain paragraphs.

*"Paragraph 11 re allowing to change mind, the 'must' suggests that this must be vocalised with every patient at every consultation – really?" (Surgery, more than 10 years qualified, Birmingham)*

*"Re 9i is this implying that we 'must' give all patients information regarding a second opinion, or only if they ask? This needs clarity." (Surgery, more than 10 years qualified, Birmingham)*

- **Discussing side effects, complications and other risks (paragraphs 28-36)**

- Overall these paragraphs were generally well received but, once again, doctors were concerned that they do not have time to adequately meet the guidance in all cases. There was also a suggestion that too much emphasis on rare adverse outcomes may cause undue distress to the patient.

*"Good in principle but how practical is it to discuss all side effects/adverse reactions, including minor ones? Every medication has a large list of potential side effects and interactions – have we got time and knowledge to give accurate information about each potential side effect and how will that empower the patient or will it not just create anxiety and poor compliance?" (GP, more than 10 years qualified, Stockport)*

- **Capacity issues (paragraphs 62-79)**

- Doctors particularly welcomed the shorter paragraphs within this section of the guidance, making it easier to read. Due to the complex nature of determining capacity, doctors would like the section to contain links to case studies and signposts to other organisations who could offer help with determining capacity issues. There were also several calls for more guidance within the section relating to establishing the capacity of patients who do not speak English.

*"Good information given in this section. Bullet points make the information much more inviting to the reader, rather than large paragraphs. It would be good to include (in the section "maximising patients' ability to make decisions") something about patients who do not speak English, stating that one must aid in their interpretation but that family members cannot be use for this etc. I'm not sure if it is written elsewhere but it would make sense to have something about it in this section." (Surgery, less than 10 years qualified, London)*

- One doctor was concerned that paragraph 76 implied that the views of others involved in care could outweigh the views of the team looking after the patient. Other doctors highlighted that the views of people close to the patient were not always in accord; that family members might not have the patient's best interests at heart; that those close to the patient on a daily basis might know the most about the patient's wishes than more immediate family members and, therefore, further clarity on 'close to the patient' was required.
- There were two suggestions that the guidance around capacity should also include when to seek a second professional opinion.

*"I think there should be a statement to at least encourage i.e. 'You should...consult with a colleague in the same speciality to aid in decision making'." (Surgery, more than 10 years qualified, Birmingham)*

- **Recording decisions (paragraph 51) and Reviewing decisions (paragraphs 52-53)**

- Most doctors were happy with the guidance contained within these paragraphs. The main point of clarity they called for was to specify what was considered as 'significant time' within paragraph 52a.

*"I agree there need to have some sort of specific time limit after which previously agree consent would no longer be valid. I think there have been court cases about this in the past as well, perhaps a couple of months?" (Surgery, more than 10 years qualified, Birmingham)*

- Again, doctors mentioned the practicalities of meeting the guidance and many felt that they did not have time to document every element of the discussion.

One doctor highlighted that they used several different IT systems during an out patients clinic which could result in duplication of information.

*"Surely we cannot document every aspect of the discussion in the records i.e. all the side effects of a drug treatment?" (GP, more than 10 years qualified, Stockport)*

*"Difficult to discuss, document and perform each and every treatment decision for each and every patient in our time-pressured, resource restricted environment." (Surgery, less than 10 years qualified, London)*

- One doctor requested that the section on reviewing decisions included something about reviewing a patient's capacity to make the decision. Others asked that the paragraph on reviewing decisions mentioned retrospective documentation, as not all discussions could be contemporaneously recorded.

## 8. Looking ahead: addressing the challenges

### Section summary:

- Doctors called for a range of support to further improve their practice on consent and shared decision making, not all of which is within the remit of the GMC:
  - Production of standardised resources for doctors which outline the benefits and risks of common treatments or procedures.
    - Although some doctors argued against this as standardised information was regarded as going against the need to tailor information to the individual.
  - Promoting methods and producing resources for explaining risks (in ways that patients understand.)
  - More evidence being made available to doctors about the risks of procedures/treatments.
  - More evidence about the overall benefits of consent and shared decision making.
  - Support for smarter ways of working i.e. using new technologies in practice.
  - Patient/public education campaigns as a way of helping patients understand the principles of shared decision making and the role their role within it. Increased training opportunities/resources.
  - More time and resources available within the NHS to ensure that doctors are able to implement good practice
- It should be noted that there has been no formal evaluation of these suggestions and they are simply the views of the doctors who took part in the research.

### 8.1 Doctors' suggested improvements

Doctors talked about a range of ideas that they thought would help enable them to better meet the principles of consent and shared decision making.

#### ***Production of resources for doctors which outline benefits and risks of common treatments or procedures***

A number of doctors called for standardised information in a range of formats (including podcasts and apps), and some worked for organisations that had already produced their own. However, no-one called on the GMC itself to produce such resources, rather they saw this as the role of the Royal Colleges.

*"So it would be nice if there was some general practice data, especially the minor surgery and joint injections and these things we do. I'd like to know what the risk of infection is in a shoulder injection from a GP." (GP, more than 10 years qualified, Stockport)*

*"For things that you've mentioned as standard, you're both trying to individualise for a patient but the bits that can be standard, they should*

*be in formats that are easy. So we should be able to send patients things to their iPhones or there should be little video podcasts around where we say, can I just leave you with this or can we show you this.” (Mixed secondary care, more than 10 years qualified, Cardiff)*

However, the dangers of such standardised information were flagged by some doctors who feel that any materials would be too generic to be useful as they wouldn't be centre specific, person specific, experience specific or co-morbidity specific. There is an obvious tension between the use of standard resources (to save time and to maximise patient understanding, where resources are well written) and the need to tailor consent to the individual.

*"This idea that we as a hospital are falling short of our duties to meet post Montgomery consent, therefore, let's do it by PowerPoint and videos because that will save a lot of time, that's fundamentally misguided, because the point about Montgomery was that another person might not have needed... a non-diabetic tall woman with a broad pelvis might not have needed this information but this woman in particular did need it. So going in this sort of group approach seems to be... I can see why they do it for time but it's fundamentally misguided if we're trying to meet the Montgomery principle.” (Psychiatrist, more than 10 years qualified, Edinburgh)*

### ***Promoting methods and resources for explaining risks***

A number of doctors felt that they would benefit from tips and materials to explain risk in particular. They reported that being able to translate risk and bring it to life in a relevant way was vital to gaining informed consent. For example, charts which show the risk in colour coded human figures each associated with a particular level of risk.

### ***More evidence available to doctors about the risks of procedures/treatments***

A number of doctors felt that they did not always know enough about the treatments and procedures they were proposing to be able to tailor the information to the patient. They called for better, more up to date evidence or signposts to where it could be found.

### ***More evidence about the overall benefits of consent***

Psychiatrists referred to evidence within their profession that showed that the extent to which the patient had shared in the decision had a positive impact on the outcome of the treatment. They suggested that doctors working within other specialisms may benefit from similar evidence highlighting the clinical value of shared decision making.

*"We've shown in psychiatry that cohesion between the therapist and the patient predicts a better outcome.....Is there any evidence that could help our physician colleagues?..... Should the GMC be sponsoring*



*research on evidence about the outcome from shared versus non-shared decision making?" (Psychiatrist, more than 10 years qualified, Edinburgh)*

### **Support for smarter ways of working**

Some doctors expressed an interest in using technology to record the consent conversation, given that patients sometimes record consultations themselves. They wanted more guidance on how such recordings could and should be used.

*"It's very easy for families to just record, I think we almost have to have an expectation sometimes that we will be recorded.....It's almost as if the GMC should try and help us and be ahead of the game. So try and say 'okay, it's likely that this is going to come in and this is what needs to happen.' To really support us rather than there be recordings and then people will be caught on the back foot. And documents to say that if it happens, it can't be spliced...' So there's almost a form to say you will be recorded but they can't edit it, it has to be kept in its entirety." (Mixed secondary care, more than 10 years qualified, Cardiff)*

### **Patient/public education campaign**

Doctors felt that patients/ the public were not always aware of their role in shared decision making. There were some calls for a public campaign that:

- Informs them that patients can refuse treatment.
- Informs them that there is an increasing focus on shared decision making and patients should not expect doctors to take all the decisions.
- Encourages patients taking responsibility.

*"I would rather much appreciate if GMC provided the guidance as they provide to us in terms of consent also to the public, to explain ... to the public what is our role as a doctor, why we consent them, why sometimes we sound like this scary horrible technician who is telling you that you will die or you will get paralysed. So I think that GMC also should provide information for patients explain to them that this is just our professional requirement, that this is for the patient good, we want them to be involved, we want them to make a decision." (Mixed secondary care, qualified outside of UK, London)*

### **A patient guide**

During the group discussions, doctors spontaneously called for patients to be made more aware of their role in shared decision making. Subsequently the idea of a patient guide was put to the doctors participating in the online bulletin board; and the idea was generally welcomed.

*"I think a patient guide is an excellent idea. It may give the patient the opportunity to understand what is intended from the consent process and*

*that way it puts the onus on both doctor and patient to complete the process effectively". (Surgery, less than 10 years qualified, London)*

*"I think a well worded and approachable patient guide would be quite useful. Perhaps focussing on what consent entails and how that interacts with the doctor patient partnership. Again, case examples for patients could go quite far in convening points. A succinct explanation of capacity would also be helpful". (GP, less than 10 years qualified, Edinburgh)*

Doctors suggested that the patient guide contain information on:

- The duties of a doctor within the consent process.
- The rights of the patient within the consent process.
- Brief explanation of capacity.
- Potential questions the patient could ask.
- Advice for patients' families when the patient lacks capacity.
- Example case studies.

### ***Increased training opportunities/resources***

There was a general call for more training opportunities around consent. Suggestions included:

- Ensuring that consent is mastered within the early years of postgraduate training (F1/F2)<sup>4</sup> with direct links to the Foundation Programme e-Portfolio.
- Training provided at particular times when doctors take on more responsibility - transition from registrar to consultant etc.
- Making such training mandatory, possibly as part of SPA, CPD or revalidation.

Some felt that the training should focus on improving communication skills that equipped doctors to have difficult conversations, often with strangers and within tight time frames.

There was a specific interest in scenario based resources or training which is tailored to different specialties, as this is more compelling than a list of principles (one suggested a podcast).

Several doctors also saw an opportunity for the GMC to support individual organisations to deliver training to their staff rather than attempt to reach out to

---

<sup>4</sup> A Foundation doctor (FY1 or FY2 also known as a house officer) is a grade of medical practitioner in the United Kingdom undertaking the *Foundation Programme* – a two-year, general postgraduate medical training programme which forms the bridge between medical school and specialist/general practice training. Being a Foundation Doctor is compulsory for all newly qualified medical practitioners in the UK from 2005 onwards. The grade of Foundation Doctor has replaced the traditional grades of pre-registration house officer and senior house officer.

individual doctors. This was partly driven by the desire for face to face sessions where scenarios could be unpicked and discussed to aid learning.

*"So it's great, online resources we all use them but sometimes you do need face to face, okay, let's do some interactive cases, let's do some small group work, you've got this situation, what are you guys going to do here?" (GP, less than 10 years qualified, Glasgow)*

*"Because culture of practice in Medicine is still at least semi vocational and it's about learning from the senior person who's your boss, belonging to a community of practitioners where you don't want to step out of line with established practice. So a lot of its delivered locally and I think help and support for organisations deploying local training, that's one thing that might be a helpful thing for the GMC to do." Psychiatrist, more than 10 years qualified, Edinburgh)*

### **More case studies/links to case studies**

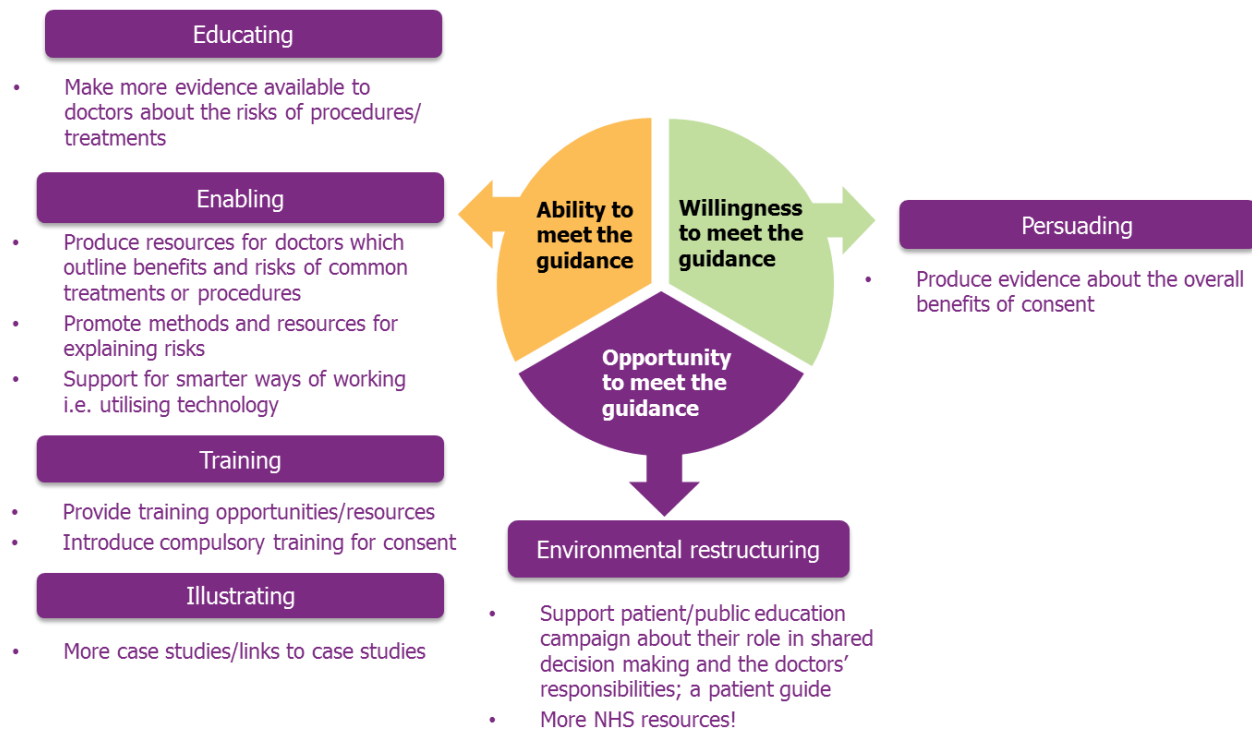
A number of doctors reported finding case studies helpful. They called for both wider promotion of current case studies and the development of more case studies that highlighted the complex nature of consent and the 'grey' areas. Doctors who reviewed the written guidance in detail often suggested that there were links from the guidance to relevant case studies and case law.

### **More time and resources available within the NHS**

Some doctors felt strongly that to meet the GMC guidelines around shared decision making, they need more resources available within the NHS to allow them time and opportunity to conduct the consent process

## **8.2 Linking solutions to challenges**

Figure 3 groups the suggested solutions under key headings and links them to doctors' ability, willingness and opportunity to meet the guidance.



**Figure 3 – Suggested solutions and how they address the challenges**

## Appendix 1 - Participant profiles

**Table 1 – Discussion group participants**

<i>Gender</i>	
Male	29
Female	17
<i>Current grade</i>	
Foundation Yr1 / 2	5
CT1	3
SHO	3
SpR	2
Consultant	21
GP	10
Other	3
<i>Time working since qualification</i>	
Less than 1 year	9
More than 1 year, less than 5	7
More than 5, less than 10	4
More than 10 years, less than 20	13
More than 20	14
<i>Where completed primary medical qualification</i>	
UK	34
EU/EEA	4
Other	9
<i>Ethnicity</i>	
White British	23
White European	7
British Asian	5
Asian	6
Arabic	5
Other	1

**Table 2 – Bulletin board participants**

Specialism	Experience	Location	Number of participants
Mental Health	Less than 10 years of experience i.e. FY1, FY2, SpR.	Leeds	3
Mental Health	More than 10 years of experience i.e. consultant	Edinburgh	2
GP	Less than 10 years of experience	Edinburgh	3
GP	More than 10 years of experience	Stockport (drawing on surrounding rural locations)	4
Surgery	Less than 10 years of experience i.e. FY1, FY2, SpR.	London	4
Surgery	More than 10 years of experience i.e. consultant	Birmingham	6
Mixed secondary care	Less than 10 years of experience i.e. FY1, FY2, SpR.	Belfast	3
Mixed secondary care	More than 10 years of experience i.e. consultant.	Cardiff	3
Mixed secondary care	All trained outside of the UK and/or English as a second language	London	0

## Appendix 2 - Summary of specific comments on the guidance

Paragraph	Comments
8	May read better as 'Clinicians/doctors should discern:'
9(g)	<ul style="list-style-type: none"> <li>The list of people involved in delivering hospital care is very long – is it really a MUST?</li> </ul>
9(i)	<ul style="list-style-type: none"> <li>Call for further clarity around as some confusion about whether doctors MUST give ALL patients information about their right to seek a second opinion or only give this information to those patients who ask for it</li> </ul>
11	<ul style="list-style-type: none"> <li>Suggests that the right for patient to change their mind has to be vocalised to every patient at every consultation. Question whether this really is the case?</li> </ul>
13-17	<ul style="list-style-type: none"> <li>Useful guidance for times when patients with capacity do not want to know details of their condition/treatment</li> </ul>
15	<ul style="list-style-type: none"> <li>'Very interesting' as suggests that consent may be invalid if patient refuses to know about and investigation or treatment</li> </ul>
21	<ul style="list-style-type: none"> <li>Suggestions are not always practicable – 'unspoken anxieties'; 'audio record'. Comment that the paragraph is about how to communicate effectively and, as such, should not be within the guidance</li> </ul>
25	<ul style="list-style-type: none"> <li>Needs more information/explanation; reference provided not thought to give any additional information; should "seriously" be defined</li> </ul>
32	<ul style="list-style-type: none"> <li>'You must tell patients if an investigation or treatment might result in a serious adverse outcome, even if the likelihood is small' concerns one doctor who highlights that every intervention carries a small risk of serious complications (even an x-ray). Therefore might be impossible to meet the guidance within normal medical practice</li> <li>Does 'frequently' need defining?</li> </ul>
33	<ul style="list-style-type: none"> <li>'You must give information in balanced way' may be difficult to achieve as left to the discretion of individual doctors</li> </ul>
28 and 31	<ul style="list-style-type: none"> <li>Offer similar information; opportunity to condense?</li> </ul>
51	<ul style="list-style-type: none"> <li>Does it need to include situations where the patient is not making the decision?</li> <li>Maybe helpful to expand on 'key' within 'key elements of your discussion'</li> <li>Uncertainty that current surgical consent forms can capture the depth of information that the guidance is requiring doctors</li> </ul>
52	<ul style="list-style-type: none"> <li>Replace should with MUST in 'Before beginning treatment, you or a member of the healthcare team <i>should</i> check...'</li> </ul>
52a	<ul style="list-style-type: none"> <li>Is there a need to specify what a 'significant time' means i.e. 1 month, 6 months, 12 months?</li> </ul>

53	Re 'progress of their treatment' it might be worth expanding guidance to cover situations where the treatment i.e. who is responsible for keeping patients informed - nurse , colleague, junior doc etc
69	Highlighted as impractical by one GP who is concerned about the additional time it would take to offer patients written records of discussions.
70	Provide links to example documentation; expand on the validity criteria and the role of advance directives
76(f)	Concerns around MUST consider 'the views of people close to the patient' as there are often disagreements with families that put pressure on the healthcare team; how do you define 'close'
79	States doctors '...can treat without their consent, provided the treatment is immediately necessary...' but one doctor asked the question of whether doctors MUST treat



## Appendix 3 - Research instruments



Final discussion  
guide.docx



Hypothetical  
scenarios.docx



Bulletin board  
questions.docx



GMC Consent  
Guidance